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Cancer Patients' Pathways: Evidence and Implications for Policy

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ICCA Tanzania

Cancer patients' pathways: evidence and implications for policy¹

Working Paper

Summary

This Discussion Paper presents findings from a patient pathway survey conducted in 2019 with 62 Tanzanian participants suffering from cancer or survivors of cancer. The paper looks at facilitators and barriers to accessing cancer care in Tanzania. A number of identified challenges that hinder patients from accessing care in a timely manner relate to costs, diagnosis and referrals. The paper highlights the social and economic burden faced by patients on the path to treatment.

The research forms part of a larger collaborative project, *Innovation for Cancer Care in Africa (ICCA)*. The survey included an innovative methodology, tracing in detail patients' pathways through their experience of cancer from first symptoms to diagnosis to treatment and after. Key findings in this paper include the following.

- Late-stage presentation of cancer is acknowledged to be a serious impediment to effective treatment in Tanzania. The average delay for these patients between first going to a health facility with symptoms that were those of cancer, to diagnosis, was 2.13 years. This delay is a central cause of late stage presentation for treatment.
- In their search for a diagnosis, many patients have moved repeatedly between formal facilities as their (often severe) symptoms worsened. While most public sector patients had to move "up" the system, from district to zonal or national level hospitals to obtain a diagnosis, only 15% of all these movements between facilities were the result of a referral. Most were patients' (and their families') search for diagnosis.
- Regional hospitals, to which many patients moved from district level, did not do well in terms of diagnosis; only 8 people were eventually diagnosed at regional level including none who began their pathways at that level.
- Several patients had been well served by dispensaries and district hospitals: two directly diagnosed there, and several moving directly to the facility where diagnosed: there is thus some good practice at district level to be shared.
- Two patients were diagnosed through screening, both after several moves between formal health facilities, evidencing both the importance of screening and the lack of effective investigation of symptoms within the system.
- Out-of-pocket costs were high for patients in the period when they were seeking treatment, an average of over TZS 400,000. For those on lower household incomes in particular, this

¹ This ESRF Working Paper presents findings from a patients' pathways survey conducted in 2019 with 62 Tanzanian participants suffering from cancer or survivors of cancer. The research forms part of a larger project, *Innovation for Cancer Care in Africa (ICCA)*. The support of the Economic and Social Research Council (ESRC) (UK) is gratefully acknowledged. The content of this working paper is the sole responsibility of the authors and does not necessarily reflect the views of the UK ESRC. In Tanzania, the project is led by Fortunata Songora Makene at ESRF, and the research brings together an interdisciplinary team encompassing sociologists, statisticians, economists, clinical oncologists and industrial pharmacists' expertise. The larger project brings together researchers from Tanzania, Kenya, India and the UK to address the opportunities and challenges of linking industry and health systems in order to widen access to cancer care in Tanzania and Kenya. Research and Ethical Clearances were sought and obtained from NIMR, COSTECH, NBS, PORALG, and Regional Offices in Dar Es Salaam, Pwani (Coast) and Tabora, and the Open University, UK.

had imposed a major burden and source of impoverishment. This effect was worsened by the addition of transport costs of moving between facilities.

- Patients starting in the private sector, generally with NHIF or private insurance, experienced shorter and more direct trajectories to diagnosis. Insurance was only partially financially protective before diagnosis, reducing on average but not eliminating out of pocket (OOP) spending.
- Delays between diagnosis and treatment were much shorter: average 16 weeks to start of treatment. A cancer diagnosis triggered, on average, burdensome continuing costs: while half of respondents made no OOP payments after diagnosis, the average payments for all respondents were over TZS 1.6 million. Of those who made these payments, 80% had no insurance.
- Over half of respondents said they had used a complementary or alternative form of care. For many this was prayer and faith healing, sometime associated with other forms of mosque or church support. Those who went to alternative healers and gave cost details had spent an average of nearly TZS half a million.
- Free treatment at Ocean Road Cancer Institute (ORCI) is effective in protecting many lower income patients, who made up the majority of respondents interviewed at ORCI, from prohibitive costs of treatment, and is hugely appreciated by patients.

1. Introduction

Cancer is the second leading cause of death globally, and is responsible for about 9.6 million deaths in 2018 (WHO, 2018). Globally, about 1 in 6 deaths are due to cancer. Cancer is a sharply rising disease burden in Tanzania. According to WHO (2020) for Tanzania there was a total of 42,060 cancer cases in 2018 and 28,610 cancer deaths in the same year. About 35,000 people develop cancer each year, and recent forecasts suggest that by 2020 this number will increase by 50% (URT, 2017). Cancer is known to be diagnosed late, and services are concentrated in a few regional centres. High mortality rates result from late presentation by patients with potentially curable cancers. Access to treatment is hampered by a variety of factors including scarcity of essential items and cost of accessing care.

Currently, there are a number of policies in place that provide access and reduce the burden on individuals with the chronic disease. Institutional capacity and policy options can be limiting for cancer in Tanzania. At the national level, the Tanzania Development Vision 2025 mentions the increasing incidence of NCDs like diabetes, hypertension, coronary heart diseases, and cancer and the need for a multi-sectoral approach to health interventions. The Second Five Year Development Plan 2016-2020 (FYDP II) (2016) notes that diseases are major barriers to development, but there is no specific mention of NCDs including cancer. The National Health Policy 2017 puts in place policies to address various forms of cancer and improvement of community access to cancer management and treatment. In addition, Tanzania has a National Cancer Control Strategy (NCCS) 2013-2022 (2013) which addresses cancer prevention, early detection, improvement of diagnosis and treatment including palliative care. Furthermore, the NCCS aims at improving cancer surveillance, registration and research.

This paper offers important insights into cancer care in Tanzania as it has been experienced in recent years by patients currently or recently undergoing treatment for a range of cancers.²

2. Methods

2.1 Ethical considerations

A research permit and ethical approval was obtained from the National Institute for Medical Research (NIMR), Tanzania Commission for Science and Technology (COSTECH), the National Bureau of Statistics (NBS) and the President's Office – Regional Administration and Local Government (PORALG) to adhere to Ethical Principles and Guidelines for the Protection of Human Subjects of Research in accordance with Tanzania's Research Policy and Standards. All informed consent included the ethical components stating the objectives and content of the study, privacy and data security, voluntary participation, the right to refuse to answer or skip any questions without consequences, and information on who to follow up regarding complaints or further information on the study. All participants signed the consent immediately prior to the interview. Enumerators were trained and received instruction on ethical data collection and informed consent prior to data collection. For confidentiality, all raw data have been kept in a secure place accessible only to ESRF and Open University, UK researchers. Voice records of in-depth interviews will be destroyed after the study is finalized.

² The research team is grateful for the time and commitment of all their interviewees, many responding despite serious illness. The commitment of our interviewers Samwel Ebenezeri, Teddy Rucho, Nicholas Lusingu, Ikunda Njau, Rehema Paul, Wilfred Massau, Janeth Telekako, and Habambi Habambi in undertaking these interviews with sensitivity is appreciated. Thanks also to all participants who participated in feedback workshop held on the 10th of December 2019.

2.2 Geographical locations and sampling

Data for the study were collected from three regions in Tanzania Mainland that were purposively selected to support comparative analysis: Dar-es-Salaam, Pwani and Tabora Regions. Dar es Salaam is the commercial capital. It hosts the national cancer hospital at the Ocean Road Cancer Institute (ORCI) and the national level hospitals able to offer cancer care at Muhimbili and Mloganzila. Pwani and Tabora offer insights into patient experience close to and further from the resources of the commercial capital to the national hospitals.

To recruit participants for the survey, patients who were undergoing cancer treatment at Ocean Road Cancer Institute were asked to participate, and 40 agreed to participate in the study. In addition, in Dar es Salaam, seven patients at Aga Khan Hospital were interviewed, and six cancer survivors. Outside Dar es Salaam, nine cancer patients at Kitete and Tumbi regional hospitals were also interviewed (Table 1). The medical staff in respective facilities assisted in identifying patients who could take part in our study. Cancer survivors were interviewed at the hospital where the contacts were obtained or alternative places convenient for them. The small numbers of participants in Kitete and Tumbi hospitals can be attributed to the fact that the regional hospitals are presently able to provide only initial screening/diagnosis for cancer patients.

For interpretation of the findings presented in this paper, it is important to keep in mind that we interviewed only patients who were undergoing treatment, about to start treatment, or having completed treatment. There was no way to reach people who had dropped out of the system before or after diagnosis.

Table 1 Survey participants by location of recruitment and interview

Location	Number of participants
Ocean Road Cancer Institute, Dar es Salaam	40
Kitete Hospital, Tabora	4
Tumbi Hospital, Pwani	5
Aga Khan Hospital, Dar es Salaam	7
Cancer survivors, Dar es Salaam	6
Total participants	62

2.3 The survey instrument and data collection

The survey for which we report the findings here was a demanding experience for interviewers and participants. The survey was developed in English then translated in Swahili for the Tanzanian Swahili speakers. The survey was administered through a tablet; subsequently the responses were translated into English.

The interview began with structured questions eliciting some basic socio-demographic information from each participant (age, sex, schooling, marital status), plus information on income, place of residence and size of household, and occupational status, both current and before the illness. Other closed questions included the use of alternative health treatments; insurance arrangements; and participants' social support and information networks. Open questions asked for reasons for use/non-use of alternative healing, and views on the availability, affordability, adequacy, and acceptability of treatment and diagnostic practices.

The core of the interview elicited a narrative account of each participants' "pathway" since they first noted symptoms which were later identified as cancer. To elicit information about patients'

journeys, the enumerator asked how long ago patients had experienced the first symptoms, and to use the following prompts for each step in the patient's narrative:

- What did you do?
- Where was this?
- What was done?
- How much did it cost, and how much did you or your family/friends pay from your own funds?
- Did any insurance cover part of the cost? Which, and how much?
- How did you travel?
- And then what happened?
- When was this?

Each pathway would contain as much or as little detail as the patient would want to or could share, so length and depth varied greatly among patients.

Most interviews lasted for about one hour, although some lasted for about two hours. The average number of key events recorded was 10, but four patients reported as many as 30 key events. The process was stressful for interviewers as well as patients, since these are painful stories. The participants shared their stories either privately or in a room with several other patients who also provided peer support. Some interviews were interrupted because the patient needed medical attention or was too tired, and resumed only if that was the wish of the patient. Participants and their carers did express a wish to tell their stories and several said that they felt listened to.

The survey data other than pathways were recorded on a tablet. The pathways section was recorded on paper to allow flexibility in compiling the narrative, and the information was transferred to the tablet at the end of each day. Workshops with the enumerators helped to capture the detail needed to analyse patients' health seeking behaviour and experience.

2.4 Methods of analysis

Analysis of the participants' narratives has used a mix of quantitative and qualitative methods. Each patient's pathway was entered into the format of a matrix, where each row shows an event, starting from the first event, that is the first symptoms, and then following rows recording each event

These pathways data have been analysed using Stata14. Data cleaning and interpretation for quantitative analysis have included measurement of time between major milestones for the patient: first symptoms, first entry into the formal health care system, cancer diagnosis, and start of cancer treatment. There are rich data on payments out of pocket for consultations, diagnostics and treatments, and the burden these payments impose on patients and their families. The quantitative analysis reported shows the experiences shared by survey participants may be related to their starting point within the health care system; their household's ability to support their health care costs including support networks and whether they have insurance; and respondents' use of alternative treatments.

In addition, the replies to open ended questions, and aspects of the narratives, have been analysed using NVivo11 to code and link emerging themes.

2.5 Innovative aspects of the pathways method

The precise form in which the pathways approach is developed and used in this project is an original contribution to the literature. Its format and data recording approach is drawn from the economics literature on household time budget studies. There are some similarities and contrasts with the way

in which concepts of “pathways” are currently used in the health systems and clinical health management literature. That literature distinguishes clinical and care pathways from other patient pathways approaches.

The literature on clinical pathways generally provides evaluations of treatment packages with a view to reduce costs and to improve outcomes by standardising treatment (Rotter et al. 2012; Dahlin and Raharjo 2019). Most of this literature is hospital based and is focused on defining best practice. A limitation of this approach, it has been noted, is that “the roles of patients and their relatives [are]...underreported” in the pathway definitions (de Bleser et al 2006). A somewhat broader approach is taken in the “care pathways” literature: here, pathways are normative “tools to organise patient care” (Vanheacht et al 2012:28) or “assist in providing general guidelines” for care (Coughlan et al (2006:138). They are more likely to be nurse focussed and/or to include pathways outside a hospital setting. Vanheacht et al (2012) list related definitions of these pathways, and argue that it is hard to evaluate these pathways in practice, because they inevitably reflect complex interventions strongly dependent on context.

Alongside this evaluation literature on clinical/care pathways, there is a related, more exploratory literature modelling patient flows, and examining the extent to which standard clinical pathways are adhered to. This involves tracing actual patients’ routes through care, using methodologies more akin to our own. These methods have been used to construct standardised pathways for clinicians and managers to implement e.g. in Russia (Kontsevaya et al 2018), and in Europe) Adeyemi et al 2013).

Finally, there is a smaller but growing literature on “patient pathways” used to understand patients’ experience and points of view (e.g. in Europe, Salamonsen et al 2016, and in Africa Kauye et al 2015; Mhalu et al 2019). Much of this latter research is qualitative, often with small numbers of respondents, and links to an expanding literature on “patient-centred care” (e.g. Kitson et al 2012). Some of the work focuses on patient’s pathways until they start treatment (e.g. for Africa, Kauye et al 2015; Mhalu et al 2019). Other studies follow the pathways through treatment (e.g. Salamonsen et al 2016). A systematic review of delayed presentation and diagnosis of breast cancer in African women (Espina et al 2017) distinguishes patient-mediated (e.g. socioeconomic status) and health system-mediated (e.g. referral problems) delays but makes the point that they are interrelated. That review addresses what they call “navigation pathways” followed by patients for accessing treatment, and the review also notes that none of the articles surveyed combined health care providers’ views with patients’ views, relying only on patients’ reporting.

In this project, several aspects of the use of pathways are innovative. The sample size is larger than many previous qualitative patient pathways studies. The extent of the information recorded is unusually broad and detailed. And the use of quantitative methods to analyse the pathways, associated with qualitative analysis of themes, is original within the literature. From a qualitative point of view, it was important not to predetermine the issues patients would want to share, while at the same time creating a systematic framework for collecting details of patients’ experiences and health seeking behaviour in a form which, as far as we are aware, has not been used with this breadth before in Tanzania.

3. Findings

3.1 The participants: socio-economic characteristics

Most of the participants were undergoing cancer treatment when interviewed: 52 out of 62 (83%). The exceptions were in the regional hospitals, where half were on treatment when interviewed, and the survivors.

Only adults were interviewed. The age range was wide, with the largest age group 45-54 (Figure 1). A majority (71%) were women.

Figure 1 Ages of survey participants (years)

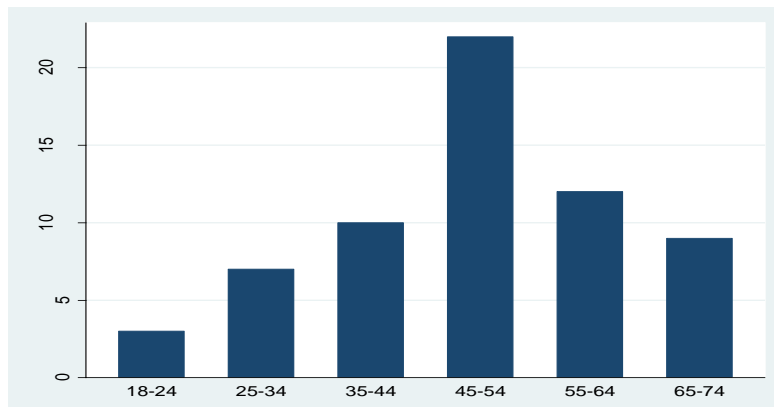
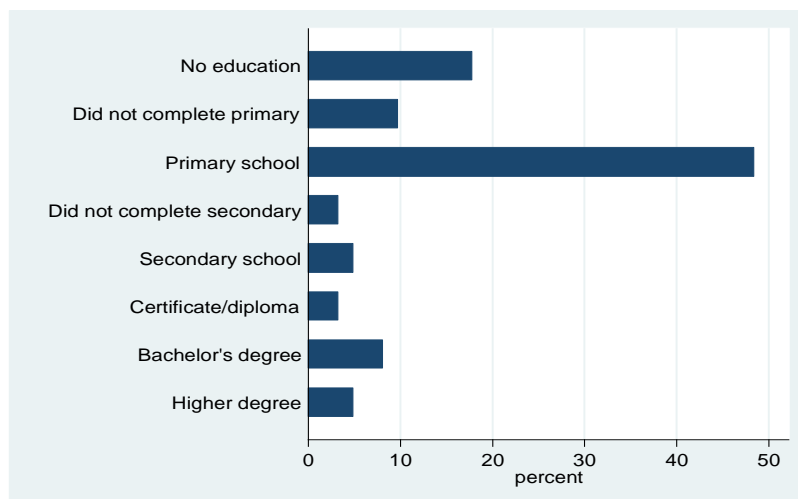


Figure 2 Educational level of survey participants (percentage of all participants)



A large majority of those interviewed had low educational levels (Figure 2). This was particularly true of those interviewed in public sector hospitals, mainly in Ocean Road. Of these, 90% (44 out of 49) had primary school education or below. Conversely, four of the seven patients interviewed at Aga Khan, and half of the survivors interviewed, had degree-level education.

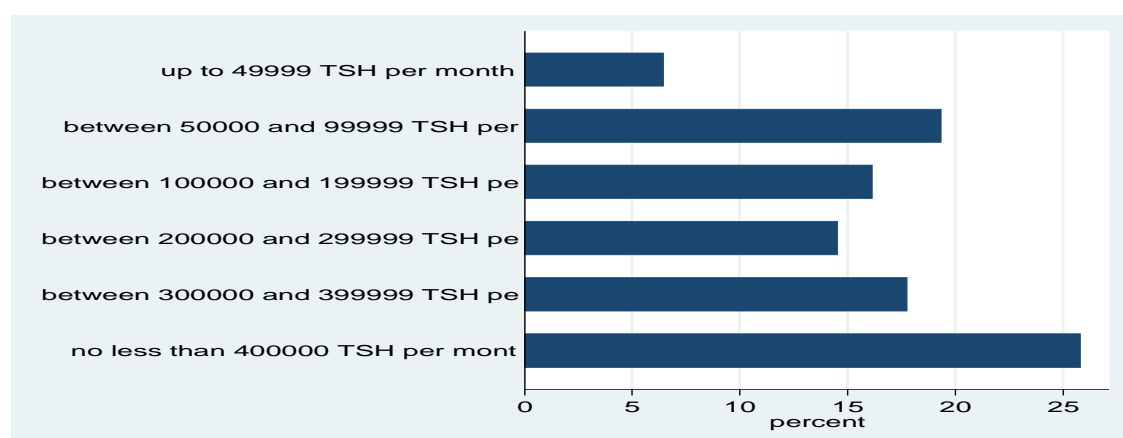
The majority of the study participants had been engaged in some form of economic activity before their illness (Table 2), the largest categories being farming, business and the professions. At the time of interview however, just over half stated that they were economically inactive (not working or retired). The implications of cancer for livelihoods are stark in these data.

Table 2 Occupation of Respondents before illness and when interviewed

Occupation	Before illness	When interviewed
Business (self-employed), casual worker	13 (21%)	8 (13%)
Farmer (large or small scale, gardening)	27 (44%)	11 (18%)
Employed professional e.g. teacher, doctor	13 (21%)	10 (16%)
Student	1 (2%)	1 (2%)
Retired	2 (3%)	2 (3%)
Not working	5 (8%)	30 (48%)
Other unspecified	1 (2%)	
Total	62	62

Declared household income levels at the time we met the participants varied widely, but 51% declared household income of under TZS 200,000 (less than USD 90) per month (Figure 3). Insurance coverage of some kind was held by 24% of participants, not including any in the lowest income band.

Figure 3 Participants' household income per month



The study participants interviewed at the Ocean Road Cancer Institute (ORCI) and at the two regional public hospitals were predominantly from lower income households; a large majority were uninsured; and they were predominantly of lower educational background. The national cancer hospital thus genuinely appears to be serving, on this evidence, a wide socio-economic range of the population. Insurance cover of some kind was accessed during their pathways by 43% of the patients interviewed. However, while all but one Aga Khan patient and all but one of the survivors stated they held private, National Health Insurance Fund (NHIF), National Social Security Fund (NSSF) and/or employer insurance, only 31% of those interviewed in Ocean Road and the other public hospitals had accessed any insurance at all. Furthermore, these latter forms of insurance included a number of local schemes and forms of local fundraising, Community Health Insurance Fund (CHIF) and fee waivers, likely to provide much less financial support in total; only 6% of the public hospital interviewees had NHIF. No interviewee in the lowest household income bracket had any insurance access. The participants interviewed at Ocean Road, furthermore, gave home regions that were widely scattered geographically. Those interviewed at Kitete all gave Tabora as their home region, while at Tumbi, all but one participant was from Pwani region. All of the participants at Aga Khan gave their home region as Dar es Salaam, and most (83%) of the survivors interviewed did also. For the latter group, this reflects the method of recruitment.

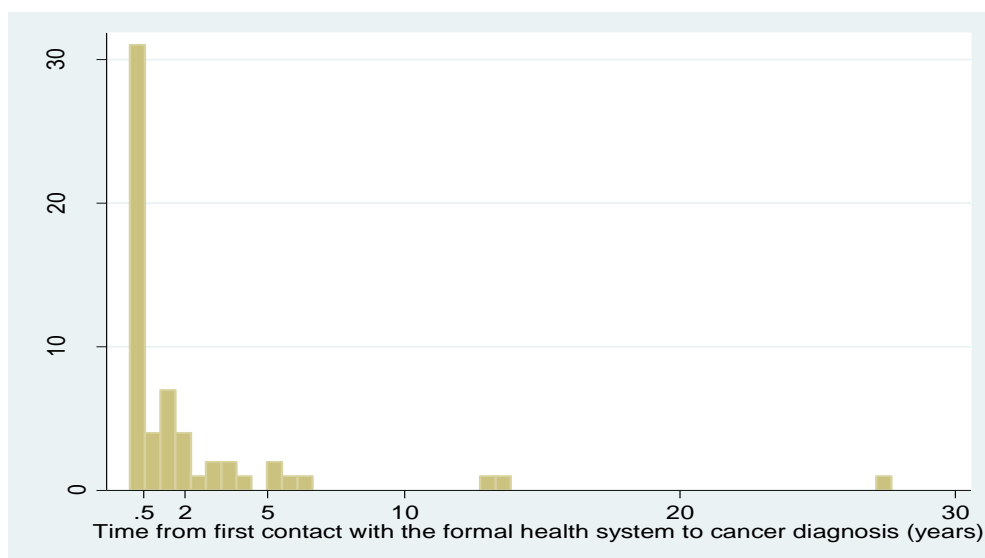
3.2 Delays: extent and pattern

As noted above, a high proportion of cancer patients in Tanzania have reached treatment only at a late stage in their illness, reducing the chances of effective treatment. The pathways narratives reported here provide substantial insight into the extent, nature and pattern of delays experienced by patients. The narratives begin from the first symptoms, and many patients experienced long delays between first noting the symptoms and receiving a cancer diagnosis.

Not every pathway's timeline can be measured accurately in terms of delays between stages, but most provide enough data for good estimates. Perhaps the most important measure for policy is the delay experienced between the first time a patient went to a formal health care institution with symptoms that turned out to indicate cancer, and reaching a diagnosis. The average delay before diagnosis for these patients was 2.13 years.

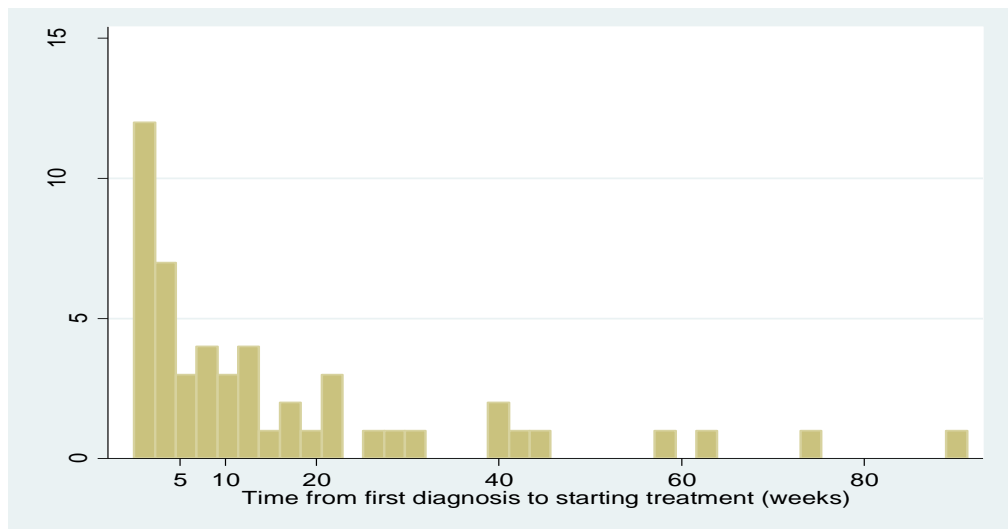
The range however was very large as Figure 4 indicates. A quarter of these patients were facilitated to reach a cancer diagnosis within three months of first going with their symptoms to a health facility (not including a pharmacy or drug shop or alternative healer); 44% received a diagnosis within six months. Others had suffered longer or very long delays: 44% had waited over a year, and a quarter of respondents had waited two years or more.

Figure 4 Years from first contact with formal health system to first cancer diagnosis



Delays from diagnosis to treatment had been, fortunately, shorter (Figure 5). A quarter of the patients had started treatment within 2.4 weeks of diagnosis; 40% in under 6 weeks. However the average wait was 16.2 weeks, and 9% waited over a year.

Figure 5 Number of weeks from first diagnosis to start of treatment



The results of these delays, especially before diagnosis, are clear in terms of late stage presentation for treatment. Also clear is the potential well being benefits to patients of reducing those delays. We explore the pathways data here to disentangle sources of delay before diagnosis: the barriers and facilitators patients have faced in their search for a diagnosis.

3.3 How does starting point influence delay before diagnosis?

Although some people waited too long before presenting their symptoms at a facility, most of the delay before diagnosis occurred *after* the patient had sought care in the formal health care system. Of 62 participants, just 20 narrated events addressing their symptoms (such as staying home, self-medication from a pharmacy) before they first went to a health facility. The average delay before first going to a facility for that group alone was just under six months (median three months), with wide variation; the other 42 participants had gone straight to a facility.

The pathways allow us to explore the extent to which the delay a patient experienced was influenced by their point of entry into the formal care system: the level of facility which they first visit. The results suggest some possible policy recommendations.

Table 3 summarises, for all interviewees, the level at which they brought to the health system the symptoms later diagnosed as cancer, and the level at which they were diagnosed. Of the 49 patients interviewed at Ocean Road and the two at regional hospitals, most (69%) had started their engagement with the formal health system at a dispensary, health centre or district hospital (including the District Designated Hospitals (DDHs) with charitable status but within the public system). However 22% of those patients presented their symptoms directly to a zonal, regional referral or in one case national hospital. So as would be expected, patients on average needed to move “up” the hierarchy of the health system in order to find a diagnosis. However, some of those patients were diagnosed at district level. Most strikingly, as the patterns sketched in the figures below show, there was a huge amount of moving around, and “up and down” the system for many patients, as they tried to find out what was wrong with them. The length of time this search took was a key determinant of late or earlier presentation.

Table 3 Level of entry into the formal health care system and level at which diagnosed

Level of the health care system	Level at entry (number of participants)	Level at diagnosis (number of participants)
---------------------------------	---	---

Screening outreach		2
Dispensary or health centre	17	
District hospital including DDH	18	4
Other faith-based facility	2	4
Private facility	11	13
Regional referral hospital	8	8
Zonal hospital	4	10
National hospital	1	18
Total	61	59

Note: level of entry for one patient is unclear; level of diagnosis for three patients is unclear.

Of the 13 patients interviewed at Aga Khan or as one of the survivors' group interviewees, 77% (10) had started at private facilities, and one at a regional hospital. Just two had started at dispensary level. Of these 13 patients, 8 (62%) had gone on to be diagnosed in the private sector, 3 at national hospitals, and one at a zonal hospital (for one, level of diagnosis is unclear).

So how did these different starting points influence the time from first contact to diagnosis? Table 4 summarises the delays experienced before diagnosis, according to the starting point. Those who started in the private sector had experienced substantially shorter delays than the rest of the patients, and with relatively low variation. For the majority who started in the public sector, those who had gone directly to a zonal hospital had experienced the shortest average delays. Those who had started at district hospital level had waited on average about two years. The longest average delays were experienced by those who had started at a regional referral hospital or at a faith-based facility other than a DDH. (The very long delay when starting at a national hospital was the result of fear and refusal to take suggested tests.)

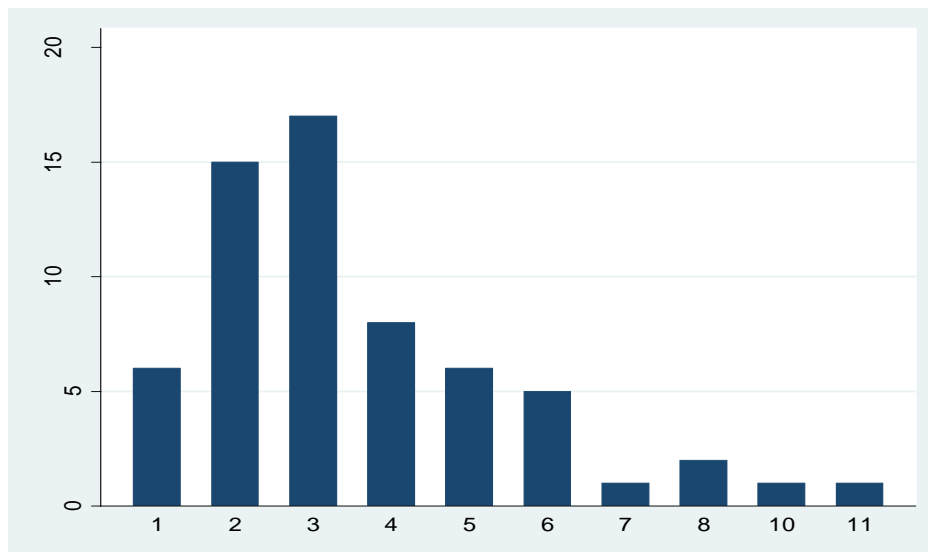
Table 4 Time to diagnosis, by level of first contact with health system (years) (all participants)

Level of first contact	N	Mean time to diagnosis (years)	Median time to diagnosis (years)	SD
Dispensary or health centre	15	3.14	1.08	6.95
District hospital including DDH	18	2.02	0.65	3.30
Other faith-based facility	2	6.66	6.66	8.98
Private facility	11	0.69	0.37	0.91
Regional referral hospital	7	2.35	2.09	1.84
Zonal hospital	4	1.17	1.37	0.59
National hospital	1	6.00	6.00	
Whole data set	58	2.26	0.92	4.30

Note: Reliable data for the length of this delay are unavailable for 4 patients, and for one of those, level of entry is unclear.

The narratives of patients' and survivors' pathways to diagnosis allow us to explore the movement from facility to facility that patients experienced on the route from their starting point to a diagnosis. The median number of facilities visited up to diagnosis was 3, but many patients visited many more in their struggle to find out what they were suffering from (Figure 6). Just six people were diagnosed (sometimes after many visits) at the first facility they had approached.

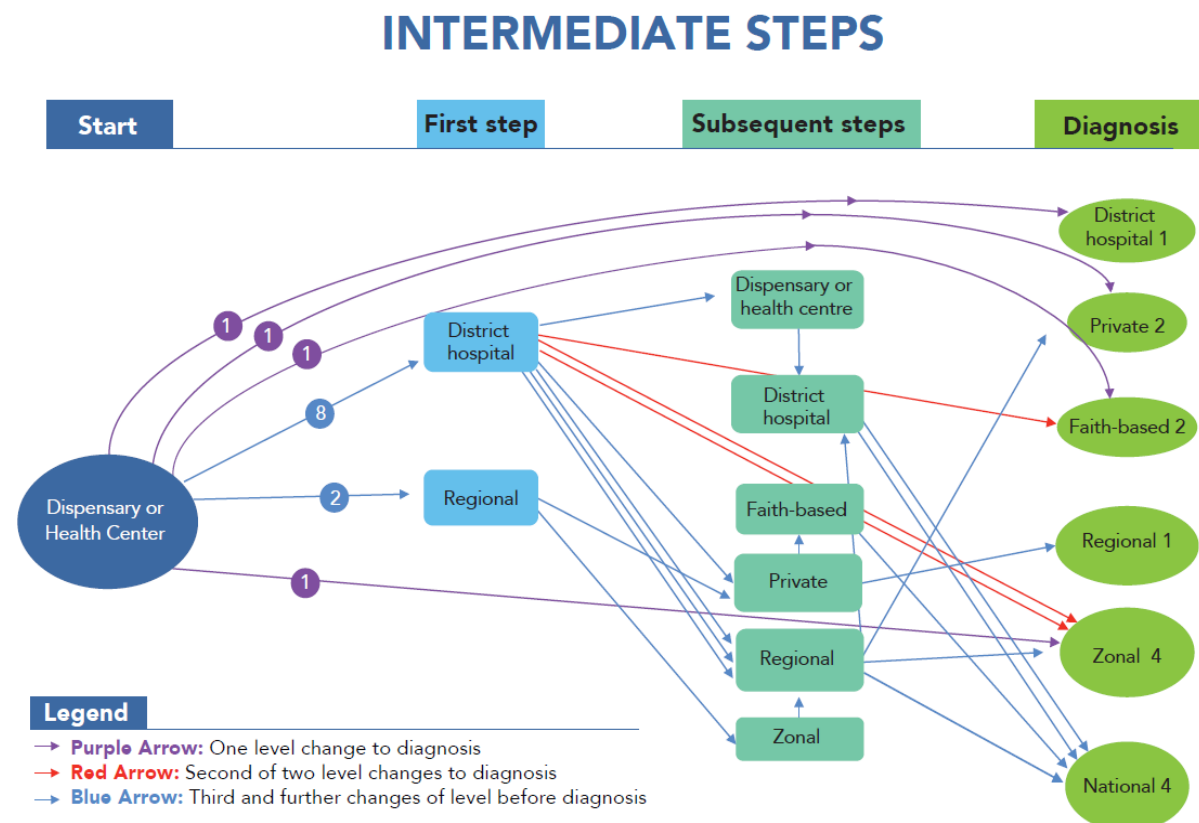
Figure 6 Number of facilities visited from first visit to a facility to the facility where a cancer diagnosis was received.



Figures 7-10 illustrate some aspects of these patterns. The figures show, to simplify a little, just the steps made between *levels* of the system, by the 57 patients for whom the data are clear enough to trace in this way. So they do not capture moves at the same level that are also counted in Figure 6. Many moves are “downwards” to a lower level as well as “upward” to regional, zonal or national level. These figures also do not capture of course the many times patients have returned to the same facility in search of answers. We are able to count some of those repeated visits by totalling the number of “events” into which our participants divided their experience: this is quite a good indicator of total visits. The median number of events between first contact and diagnosis was 5, average 6, but 25% of the respondents recounted between 7 and 27 events from start to diagnosis.

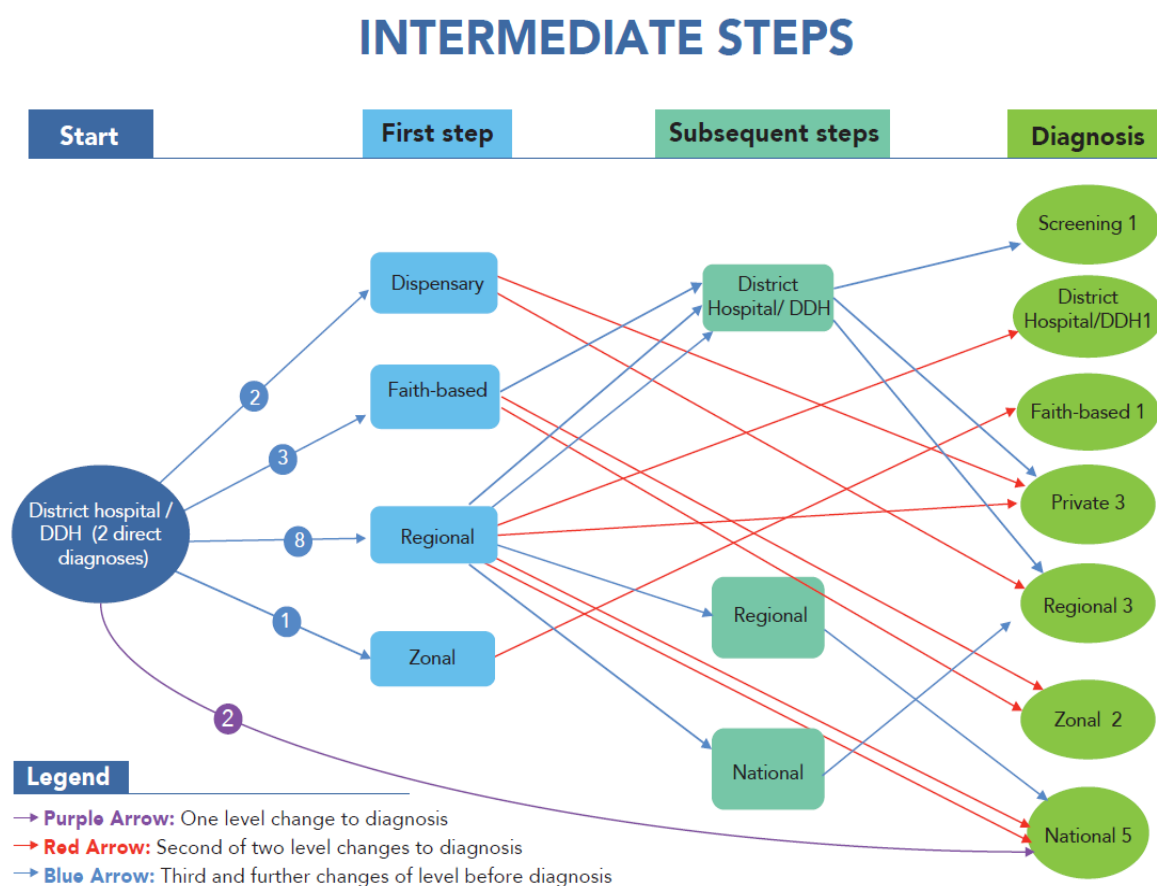
The complexity of many of the paths lying behind these numbers stands out sharply in Figures 7-10.

Figure 7 Movements between levels of the health system from first contact to diagnosis: those starting at dispensary level



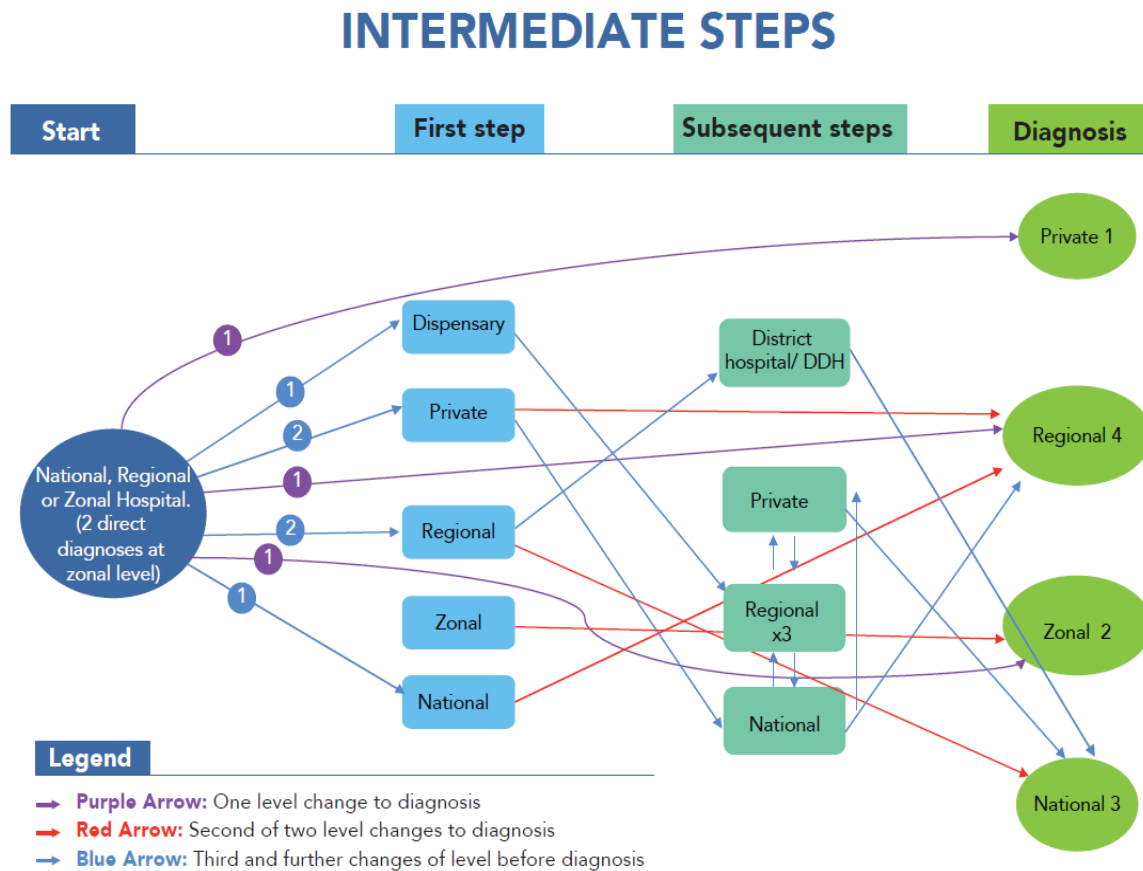
Of 14 patients who had presented their symptoms first at a dispensary or health centre and for whom we can identify the level of diagnosis, Figure 7 shows what happened next. Purple lines are a direct move from the start to the level where diagnosed; red lines are two moves across levels to diagnosis. Blue lines are single moves between levels by patients making three moves or more. Thus, four patients went from a dispensary directly to the level where diagnosed: one at district level (all district hospitals include DDHs), the others at a private, a faith-based and a zonal hospital respectively. Eight other patients went first from dispensary level to a district hospital (one army hospital is included here), from which three moved directly on to the level at which diagnosed (two in a zonal hospital, one in a faith-based facility). The remaining 50% of patients who started at a dispensary moved around much more, up and down the system (the blue arrows, one per move), experiencing three or more moves between levels and sectors of the system before diagnosis. The regional hospitals, visited at some point by half of this group of patients, did not do well in terms of diagnosis.

Figure 8 Movements between levels of the health system from first contact to diagnosis: those starting at district hospital/ DDH level



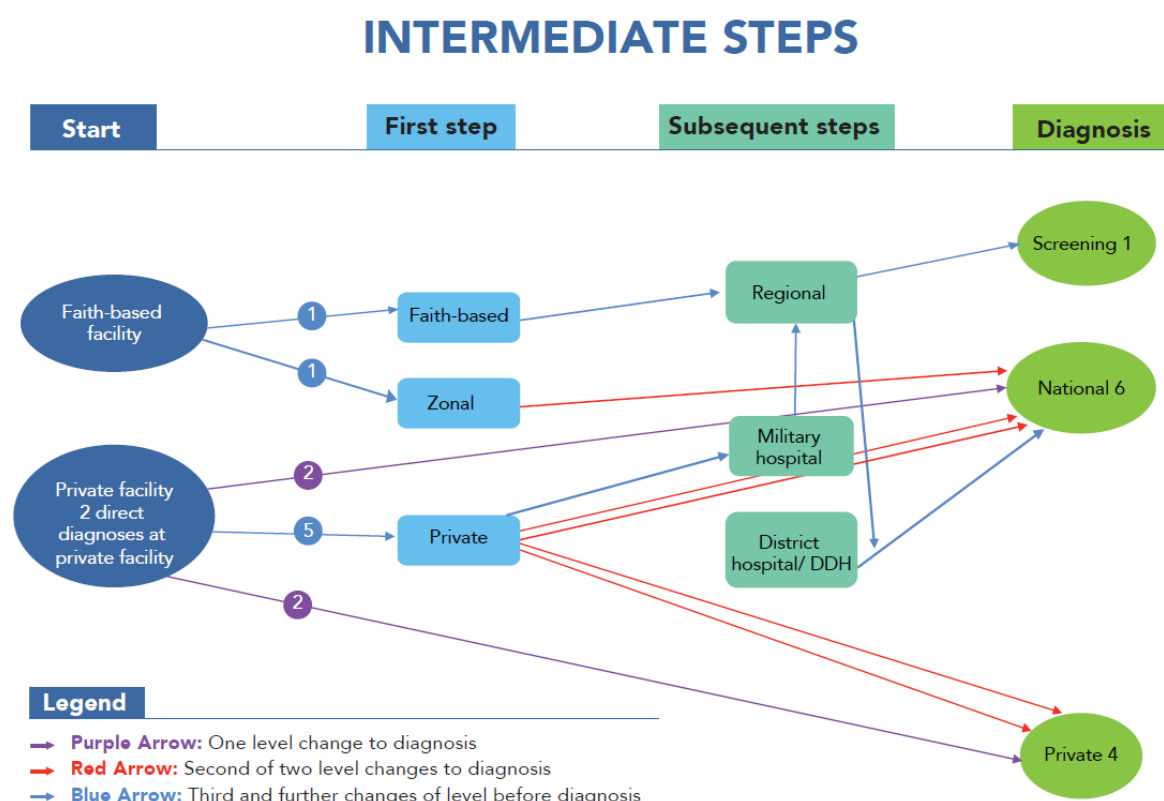
The experiences of 18 patients who went directly with their symptoms to a district hospital suggest some reasons why the pattern of moving “up” the system in search of a diagnosis may cause delays. Of these, two were diagnosed with cancer at the district facility they first approached, and two more went directly to the national level where they were diagnosed. However, for the others, the most common route was to go “up” to a regional hospital (Figure 8), but none were diagnosed at that stage. All had to move on to another level at least once in order to reach the level where they were diagnosed (Figure 8). Four others went to zonal or faith-based hospitals, and were also not diagnosed there. Some people went “down” to a dispensary or district hospital and then “back up” to a level where diagnosed. This “churning” is a clear source of delay, and was associated in many cases with severe pain and worsening symptoms. Figures 7 and 8 show that many patients had to reach national level before a diagnosis was obtained, rather than being diagnosed lower down and then being referred for treatment.

Figure 9 Movements between levels of the health system from first contact to diagnosis: those starting at regional, zonal or national level



So did it speed up access to diagnosis if a patient went directly to a higher level hospital, regional, zonal or national, when first symptomatic? Table 4 suggests this is the case for the zonal but not the regional hospitals. Figure 9 backs up this perception. Of the 12 patients who started at this level, two were directly diagnosed at the zonal hospital they first approached; three moved in one step to another regional or zonal, or a private hospital where they were diagnosed. But others moved up and down the system a striking amount: this is an unfavourable level of churning given these patients' relatively high-level start. The surprise lies in the expectation that these higher level hospitals should have more diagnostic capacity in-house than lower levels.

Figure 10 Movements between levels of the health system from first contact to diagnosis: those starting at faith-based or private facilities



Finally, Figure 10 shows the more direct trajectories experienced by patients who started in the private sector including independent faith-based facilities. As Table 4 showed, those starting in the private sector had the shortest average pathways. Of those who started at a private facility, two were directly diagnosed there, and eight made one or two more steps. Only one had a complex pathway in terms of movement between levels, and this person began at a private laboratory outside Dar es Salaam. One person starting at a faith-based facility went on to a regional hospital, but was not diagnosed until they joined a screening exercise.

Several patterns emerge from these mapping exercises.

First, rather few participants, 6 out of 58 for whom data are complete, were diagnosed at their point of entry: two at a district hospital, 2 at a zonal hospital, 2 at a private hospital, sometimes after multiple visits to that facility. Everyone else had to move around, including between levels of the system, to find a diagnosis. So speed of that movement was one determinant of extent of delay. It follows that reducing the widespread experience of apparent misdiagnosis or mistaken reassurance at the point of entry, thus increasing the chances of diagnosis at point of entry, would help to “down-stage” cancer diagnoses and treatment.

Second, particular dispensaries and district hospitals have done well in several these narratives. Two of the direct diagnoses were at district level, and two other patients starting at district level moved directly to national level for diagnosis (Figure 8 purple arrows). Of those starting at dispensary level, four moved just one level to be diagnosed (Figure 7 purple arrows). This suggests there is some good practice in the lower levels of the health system, at picking up dangerous symptoms and indeed at

diagnosis, and that this practice could be built on to speed up pathways to diagnosis and treatment. (We discuss the evidence on formal referral further below.)

Third, the performance of regional hospitals appears to be both important to speeding up diagnosis, and also, in these narratives, appears particularly problematic. A high proportion of these participants had pathways that included consultations at regional hospitals, as part of “churning” between regional and faith-based or private facilities. Nearly half of those who started at district level moved from there to regional level (Figure 8) but none were diagnosed at that stage, all moving on to other levels before diagnosis. No patients were diagnosed at point of entry at a regional hospital. Only 8 people in total were (eventually) diagnosed at regional level (Table 3); while those starting at regional level suffered longer delays on average than those starting at district level (Table 4). This strongly suggests that sharply improving diagnostic capacity at regional hospitals would help to reduce average delays across the system.

Fourth, two patients in this data set were finally diagnosed through one-off screening events (Figures 8 and 10) both having previously presented their symptoms at a regional and a district hospital respectively. This does suggest the potential benefits from integrating screening into primary care.

In contrast, those participants starting in the private sector had suffered substantially less “churning”, with those not diagnosed in the private sector moving more directly to the national level (Figure 10). Two out of 13 were diagnosed at point of entry into the system; four more moved one level to find a diagnosis and five others just two steps (Figure 10 purple and red arrows). The shorter delays involved (Table 4) do suggest the scale of benefits available from reducing “churning” for all patients. Furthermore, the narratives from the whole data set pick up the importance of private facilities also in diagnosis: a number of the movements to the private sector, for example in Figure 9, were for diagnostic testing in private facilities and laboratories. In all 12/58 diagnoses were in the private sector (Table 3).

Finally, the qualitative information in the narratives identifies another major cause of delays: long waits for tests and for results from tests. There are many cases where patients have waited months for results; had to repeat tests; and have as a result spent large sums out of pocket. It is clear there are major limitations on the ability to take and process biopsies. Here are just a few examples: note that in most cases the text is researchers’ summaries of responses; where direct speech is quoted as recorded by the interviewer, this is in quote marks.

In Muhimbili, a patient was admitted for a series of tests including CT scan, X-ray, ultrasound. The wait for the biopsy results was two months.

A patient was referred from a regional to a private hospital to have a biopsy taken. It seems the result was never available. Three months later the regional hospital took a repeat biopsy themselves and sent it to Muhimbili. Two months later the patient received the results at Muhimbili.

Cost also delayed biopsies:

At a zonal hospital, a patient with a breast lump was given an ultra sound and X-ray, and “they wanted to take sample from my breast, but I didn’t have extra money”, resulting in another five months’ delay. The total OOP cost of the repeated tests including the later biopsy was TZS 190,000.

3.4 The scarcity of formal referrals: “patient management” of the search for a diagnosis

To what extent are the moves patients make between facilities, both at a particular level and between levels, the result of formal referrals? The question is relevant because most moves before diagnosis appear to have been the patients’ own decision. We identified all the movements between facilities when respondents said that they were referred, or that they had a referral letter. On this measure only 15% of the total movements between facilities depicted in Figure 6 (an average of 3.5 moves between facilities), and partially mapped in Figures 7-10, were associated with a formal referral. All the others were the patients’ own decisions, made often with family or friends’ advice, or sometimes following a suggestion from one facility staff member that they should go to another facility.

To look at this another way, nearly half (30 out of 62 respondents, 48%) had *never* been formally referred at any point between initial contact with the health system and arrival at a diagnosis, despite all the “churning”. Of the others, 6 (10%) had been diagnosed at point of entry (hence, referral for diagnosis was not required). The other 42% had received at least one formal referral (in 7 cases, two) for one (or two) of their many moves on their way to a diagnosis. Everyone had moved more often than they had been referred, except for the six diagnosed at entry.

This finding underlies the narrative evidence in these data that, before a cancer diagnosis, when time is key to survival, patients suffered frequently very severe symptoms while waiting for a diagnosis. Their many moves from facility to facility were made, according to their own descriptions, dependent on their own and others’ assessment of accessibility, affordability and likelihood of gaining help. All patients given a referral at some point had also thus spent time moving between facilities without professional guidance. In effect, the health system’s “pathways” to diagnosis are being shaped overwhelmingly by the patients’ own care-seeking behaviour. The result is the erratic and complex movement patterns shown on Figures 7-10, and a great deal of confusion and suffering. These patterns generated lengthy delays (an average of 2.13 years) and the very severe symptoms recorded in these narratives before many patients reached a diagnosis.

The pattern of referrals experienced did vary somewhat, but not greatly, by level of entry. Of those who started at district hospitals, 67% were either directly diagnosed at that level or had a formal referral at some point in their pathways to diagnosis. For those who started at zonal level that figure was 50%. For those who started at a private facility, and for all other patients together, that figure was 45%.

Furthermore, referrals when they were offered had not always been accepted, often for cost reasons: patients were sometimes unable to afford tests. Referral patterns where they happened were complex. There was considerable churning, not only movement up the levels to the national hospitals, but also “sideways” and “down”. Two people were referred from public to private facilities for tests, both from regional referral hospitals. In one case, a dispensary aimed to send a patient directly to the national level, but this referral was refused (reason unstated) and the patient took themselves instead to a regional hospital. Another patient refused a regional to national referral because they “were advised” that it would be too expensive. A referral from dispensary to a faith-based hospital was also refused for lack of funds.

3.5 Cost as a barrier to reaching a diagnosis

As the refusals of referrals illustrated, out-of-pocket costs are a known barrier to accessing care. Only patients who have succeeded in remaining in the system could be interviewed, so we have no

accounts of experience of those who have had to drop out of a search for diagnosis because of inability to pay. The figures in this subsection are the payments made by patients who reached a diagnosis and are still in the system. Patients also commented on the problems of raising funds, and we quote those experiences below.

While cancer treatment in the public sector should be free of charge (Miranda, 2016), the consultations and tests are not, before being diagnosed with cancer. These costs can be high. People's memories of payments at each stage of their pathways were often quite sharp. In the findings that follow, the data are of course for the payments that people recalled. The out-of-pocket (OOP) payments summarised in Tables 5 and 6 are likely to be underestimates therefore, but they still give an indication of the burden of OOP payments on cancer patients before diagnosis.

In Tables 5 and 6, the average payments reported are payments by people who could remember the payments for two thirds of the events recorded. This is most of the respondents: 55 out of 62. We report the data in this way to reduce the extent of underestimation.

These patients had spent on average a recorded TZS411,831 out of pocket (OOP) on consultations, tests and treatments including surgical investigations before and up to arriving at a diagnosis. The range of payments was very wide, with 26% having made no out-of-pocket payments, and a top payment of TZS4 million. These levels of payments form a particular barrier for those from low income households.

Table 5 shows average payments out-of-pocket for care (not including transport) by declared household income band before diagnosis. Averages are distinguished between patients who recorded access to some type of insurance, and those with none.

Table 5 Mean out-of-pocket spending from first contact with the health system to diagnosis, by income band and insurance status (TZS)

Income bands	Mean OOP spending by income band			Number of respondents
	Not insured	Insured	All patients	
Up to 49,999 TZS/month	618,167		618,167	3
50,000 to 99999 TZS/month	445,600	98,333	350,892	11
100,000 to 199,999 TZS/month	213,667	570,700	302,925	8
200,000 to 299,999 TZS/month	773,333	14,666	394,000	6
300000 to 399999 TZS/month	308,000	34,000	183,455	11
400000 TZS/month and above	1,310,250	444,546	633,188	16
All participants	537,010	272,517	411,831	55

Table 5 strongly suggests that costs before diagnosis have been a major burden, especially for those in the lowest household income category, none of whom had access to any insurance. As Table 5 shows, insurance seems to have offered some protection against out of pocket spending before diagnosis, but this is limited before diagnosis and treatment, and in one household income band, those with insurance had paid more on average.

Table 6 explores this burden further. The "household burden" is calculated by dividing out-of-pocket spending up to diagnosis by *annual* declared household income. Again these data include only those who could recall payments (including zero payments) during two thirds of their events.

The average burden is 22% of household annual income, but the variation is huge. In particular, the burden on the two lowest income categories really stands out: patients from the lowest household income category had spent on average more than the annual household income; the next lowest, 48% (Table 6 column 4). Above that income level, the average burden falls below 20%. Having some access to insurance appears to have offered some protection, particularly at higher income bands (Table 6 columns 2 and 3), but not in all lower bands.

Table 6 Household burden of OOP payments from first contact with the health system to diagnosis, not including transport (multiple of annual household income)

Income bands	Mean burden by income band			N	% with insurance
	Not insured	Insured	All patients		
Up to 49,999 TZS/month	1.17		1.17	2*	0
50,000 to 99999 TZS/month	0.60	0.16	0.48	11	25
100,000 to 199,999 TZS/month	0.12	0.42	0.20	8	20
200,000 to 299,999 TZS/month	0.32	0.01	0.16	6	44
300000 to 399999 TZS/month	0.08	0.01	0.05	11	45
400000 TZS/month and above	0.14	0.08	0.09	16	73
All participants	0.34	0.09	0.22	54	41

* One very low income household declared zero current income so the burden cannot be calculated.

As Table 6 shows, 41% of interviewees declared some access to insurance. However, the types of insurance varied greatly. Just seven people stated that they held private commercial insurance (AAR, Jubilee, Strategis). All but one were in the highest income band, one in the band below. A number of people used several forms of insurance: thus twelve people held NHIF, two NSSF, two had some insurance from an employer: 13 people in all since some people had more than one, and one also held private insurance. Of those holding NHIF or NSSF or employer insurance, 70% were in the top two income bands. Seven people used some form of local insurance or facility financial support, again sometimes more than one: CHF (just one person), local schemes (unspecified), Standing Voice (a charity for those with albinism) and exemptions for age or pregnancy or poverty. Those using local schemes and charitable funds were all in the three lower income categories. Thus insurance access, as expected differs sharply by income.

Of those holding private commercial insurance, all had started at a private facility; conversely only one person starting at a private facility did *not* have either private insurance or NHIF. Of those holding NHIF/NSSF/employer insurance, 30% started at a private facility; the rest in the public sector and almost all at a dispensary or district hospital. Those using some form of local insurance or exemption had all started in the public sector and mainly at lower levels. The implication is that insurance and delay are associated, as we would expect (Table 7). Those with private insurance, with the option they mainly take up of starting at private facilities, have sharply lower delays before diagnosis. The delay advantage given by NHIF, NSSF or employer insurance is much less.

Table 7 delay between first contact with the formal health system and diagnosis, by type of insurance held (years)

Type of insurance	Mean delay	Median delay	N
Private insurance	0.54	0.04	7*
NHIF, NSSF, employer insurance	1.17	0.50	12
CHF, local religious and charitable funding	0.99	1.16	5
No insurance	3.01	1.08	34

Note: one person with “unspecified” insurance omitted.

* Includes one person also holding NHIF.

Insurance however rarely helps with transport costs. As is well known, transport costs and geographical access often constitute major barriers to care. Payments for transport were high relative to income, and insurance was not generally available. Furthermore, travel to regional or zonal or national hospitals could involve transport costs for others accompanying, and food and lodging. Sometimes, the ability to take up a referral for a diagnosis – or go to a recommended hospital in search of a diagnosis - could depend on whether a family had relatives or friends in a town or city who could house them while undergoing tests.

These patients had spent an average of TZS 48,425 on transport and travel costs before and up to diagnosis (Table 8). For the lower income patients, travel posed a severe and sometimes prohibitive barrier.

Table 8 Transport costs from first symptoms to diagnosis, by household income bands

Income bands	Mean travel spending by income band (TZS)	Number of respondents
Up to 49,999 TZS/month	93,963	4
50,000 to 99999 TZS/month	45,283	12
100,000 to 199,999 TZS/month	23,900	10
200,000 to 299,999 TZS/month	112,655	9
300000 to 399999 TZS/month	21,690	11
400000 TZS/month and above	36,972	16
All participants	48,425	62

3.6 Costs, referrals and the move to treatment

Cancer treatment is formally free in Tanzania in the public sector for those without insurance, though not all of the patients interviewed had been aware of that before arrival at Ocean Road. However, after diagnosis, patients interviewed had still faced many costs, including tests and treatment costs, as well as continuing transport cost challenges.

The analysis that follows breaks down the non-transport OOP costs into two categories: those incurred between diagnosis and starting treatment, and treatment costs. Not all of our interviewees were undergoing treatment. Some were awaiting treatment, and some, in the survivors' group, had finished treatment and were returning for check-ups. Table 9 shows the OOP payments made by interviewees between diagnosis and beginning of treatment.

Table 9 Total OOP payments from diagnosis to start of treatment, not including transport (TZS)

Income bands	Mean OOP spending by income band			N
	Not insured	Insured	All patients	
Up to 49,999 TZS/month	63,500		63,500	4
50,000 to 99999 TZS/month	527,775	145,000	423,381	11
100,000 to 199,999 TZS/month	223,750	140,785	207,157	10
200,000 to 299,999 TZS/month	45,400	0	25,222	9
300000 to 399999 TZS/month	57,833	42,500	47,000	11
400000 TZS/month and above	2,762,500	7,272,727	5,690,625	16
All participants	518,829	3,120,637	1,619,291	61

Note: one respondent omitted for whom over half the payments could not be recalled.

The variability of these payments is very high. But what stands out is a continuing burden. While cancer treatment is free at treatment point, a cancer diagnosis triggers, on average, burdensome continuing costs. Not all patients however suffered these costs. Half (31) of these patients had made no OOP (non-transport) payments between diagnosis and starting treatment, and of those, 65% (20) were insured. Of the others (30) who had incurred these costs, 80% were not insured. Furthermore, 80% of the top income bracket made no OOP payments at this stage. It seems therefore that after diagnosis, insurance became more protective, in the sense of increasing the likelihood of paying nothing. However, those who paid out of pocket in some cases paid a great deal, especially if going abroad. (We return to travel abroad below.)

The following are some examples of these continuing costs within Tanzania:

A patient diagnosed with cervical cancer at a regional hospital was referred to Ocean Road; from there, was referred for surgery at Muhimbili National Hospital at a cost of TZS 790,000, paid by the family.

A patient diagnosed with cancer at Muhimbili National Hospital was referred to Ocean Road where the family paid TZS 150,000 for a biopsy and X-ray; after that chemotherapy treatment was provided free of charge.

A patient admitted at Ocean Road (free of charge) was asked to go to a private hospital for a CT scan; the TZS 250,000 cost was paid by the family.

Surgery, tests and blood transfusions seem to have been items that quite commonly incurred charges after diagnosis and before first treatment.

Transport costs can also be a barrier at this stage, especially where treatment requires a move to Dar es Salaam. The average transport costs are lower than before diagnosis (Table 10), reflecting fewer moves. But costs could still be prohibitive, especially when people needed to find accommodation in Dar es Salaam where they had no relatives (Box 1). Of those who incurred transport costs over TZS 50,000 at this stage, over half (7 out of 13) were in the two lowest income bands.

Table 10 Transport costs from diagnosis to starting treatment, by household income bands (TZS)

Income bands	Mean travel spending by income band (TZS)	Number of respondents
Up to 49,999 TZS/month	57,250	4
50,000 to 99,999 TZS/month	46,120	12
100,000 to 199,999 TZS/month	35,625	10
200,000 to 299,999 TZS/month	25,950	9
300,000 to 399,999 TZS/month	33,827	11
400,000 TZS/month and above	11,214	16
All participants	28,993	62

Box 1: "I was living at the bus stand"

This patient with skin cancer was diagnosed at a district hospital, where a lump was removed without solving the problem. Offered a referral to Ocean Road for radiotherapy, the patient initially refused, citing the need to raise funds. The patient first tried a local healer, who seems to have charged TZS 1,500,000 (about USD 750). Four months later the

patient accepted the referral and travelled to Dar es Salaam, where the diagnostic tests were repeated and the patient had surgery at Muhimbili (costing TZS 180,000 plus transport cost TZS 39,100, about USD 110 in all). However, the patient had no money for accommodation nor relatives in Dar es Salaam, so: “during all this process and waiting time, I was living at the bus stand”, while suffering severe pain and waiting to undergo surgery. There was then a two month wait to see a doctor and then to start chemotherapy at Ocean Road followed by radiotherapy: however at that point, free treatment started, so the patient was then incurring only transport costs during treatment (totalling around USD 100 to date).

People moved less between facilities between diagnosis and treatment than when they were searching for a diagnosis, and were much more likely to have been referred at that point than before diagnosis. The median number of moves between facilities from diagnosis to treatment was just 1 (average 1.6), and 14 people did not move: they were treated where they were diagnosed. Of the rest, who made at least one move, two thirds had received at least one referral. All those who moved several times had at least one and often several referrals. It therefore seems that the referral process works more effectively *after* diagnosis than before, which is likely to be a factor in reducing delays.

Many of the moves between facilities after diagnosis, furthermore, were purposive in the sense that they were the result of referrals or proposed moves for tests or treatments not available elsewhere. There was some repetition of tests at this stage, and while repetition may be necessary to identify the most desirable treatment, it would be relevant to see whether such repetition could be minimised.

3.7 Costs of treatment and travel abroad

As noted above, not all our interviewees were undergoing treatment at the time when interviewed. Of 62 respondents, 11 had either completed treatment or had not yet started. Of the 51 respondents on treatment, 32 had paid nothing out of pocket for treatment to date. Of those paying nothing out of pocket, half had no insurance, suggesting the free treatment policy is fully protective of some patients. Of those paying something (included in Table 11), two thirds had no insurance. Conversely, of those with private insurance, only 1 out of 4 had paid OOP during treatment; of those with NHIF/NSSF or employer insurance, 8 out of 11 had paid nothing. This suggests that both the free treatment policy, and insurance are protective, but not completely.

Table 11 shows the OOP payments made by the date of interview by those on treatment. These sums are large in relation to household incomes. In addition, average travel costs within Tanzania for those on treatment, after the start of treatment, were over TZS 89,000, with very wide variation.

Table 11 OOP payments by those undergoing treatment whose OOP payments>0 (not including transport where treatment is in Tanzania) (TZS)

Income bands	Mean OOP spending by income band (TZS)	No of respondents paying OOP costs while treated
Up to 49,999 TZS/month	90,000	2
50,000 to 99,999 TZS/month	1,317,133	3
100,000 to 199,999 TZS/month	1,361,333	3
200,000 to 299,999 TZS/month	741,750	4
300,000 to 399,999 TZS/month	93,500	2
400,000 TZS/month and above	7,109,480	5

All participants	2,469,305	19
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One option open only to those with very good insurance cover or high incomes – the two are likely to be closely correlated – is to move abroad for treatment, or indeed for diagnosis. Among our interviewees are 6 cancer sufferers who have been to India and to South Africa for treatment. Two travelled to India for a PET scan; in each case the treatment cost was paid by private insurance. One patient paid around TZS 2 million out of pocket for treatment in South Africa and diagnosis in India, but also had Indian treatment paid by NHIF, NSSF and an employer. The other three paid large sums out of pocket: the average OOP payment for those three was over TZS 160 million, in addition to substantial coverage of overseas costs by NHIF and private insurance. These overseas OOP totals include travel costs. Of the 19 respondents included in Table 11, the OOP payments for four include these overseas costs, paid by patients from households in one of the two upper household income bands.

3.8 Alternative treatments: reasons, costs and delays

When people were asked about complementary and alternative treatments, two major categories of response stood out: those who found strength in prayer and faith healing, and those who consulted alternative healers. Out of 62 respondents, 34 (55%) had recourse to options other than biomedical health care. In the answers on why people used alternatives, several themes stand out.

The first is prayer and healing. Hope and belief led people to include prayer and religious healing in their search for a cure: 11 people said they had taken this route, noting the support it offered. For example:

“I’m a born-again Christian, so I believe in prayers.”

“Treatment goes in hand with prayers.”

She visited church hoping that God will do miracles because of the problem she was facing.

“We are connected through faith, so by praying I felt healed.”

Sometimes, prayer was associated with financial support from a mosque or church community.

The second route was to consult alternative forms of treatment. Some people who did so followed advice, or had seen beneficial effects for others. Some felt strongly pressured to take this route. Some feared that cancer was induced by witchcraft, and sought help to reverse that. Others simply felt that in the face of cancer, and in severe pain, people should try everything. Here are some examples of these responses:

“Someone advised me to visit a traditional healer, I visited him twice.”

“I was compelled by my mother, yet they didn't work out.”

He thought maybe the sickness was related to witchcraft thus why he went for alternative treatment.

“When you are sick, all you wish for is recovery, so you could try anything.”

“So much pain, hoping for some pain relief.”

“I saw my neighbours and friends healing so I wanted to try my chances of healing.”

These sentiments of course overlap, and in the absence of clear clinical pathways to diagnosis and treatment, this combination of care-seeking with belief and fear is a potent mix. It led many to plead for more information to be available as well as more access to conventional care. One person regretted their alternative care-seeking behaviour:

“I thought it could help me, but to be honest it delayed the process hence the problem grew up.”

Visits to traditional healers can be expensive, as Box 1 suggests. Several interviews seem to imply that it may be easier to raise money locally for traditional treatment than, for example, for transport to Dar es Salaam after a referral. The average OOP payment to alternative healers by the 15 people who provided these costs was a startling TZS 484,467. The payments varied from TZS 5000 at the lower end to TZS 6 million at the top; the median payment was TZS 30,000.

Those who gave reasons for avoiding traditional healing made it clear that these decisions are a matter of belief in a time of acute uncertainty. Some said that their religious beliefs required them to avoid traditional healers: for example: “my faith doesn't allow [this]”. Some simply did not believe in the power of traditional healing, or were afraid: for example:

“I don't believe in traditional treatment, I am educated.”

“Traditional herbs don't heal cancer.”

“I am afraid of traditional healers.”

Some responded by expressing a firm belief in medical/ hospital treatment, for example:

“I believe that the only safe place for treatment is in hospital.”

“I believed and I still believe that I will be healed in hospital.”

“Because I believe cancer can be treated and cured.”

The underlying theme here is the need for belief in the absence of much information. Unsurprisingly therefore, when participants were asked for further comments, some emphasised education and information.

3.9 Patients' perspectives on their experience: acceptability, failures and additional commentary

When asked about sources of support, most people (79%) said family; 19% said friends; while 9 (15%) said neither of those two groups. In all 14 (23%) cited community, local, group and voluntary support. The latter percentage is not large, focusing attention on a lack of wider social support, associated with the stigma some have experienced. Furthermore, overwhelmingly (94%), people said their ability to work have been affected by their illness.

When asked about the acceptability of different aspects of treatment, there were rather few responses; two people said they had refused radiotherapy as unacceptable, and one had refused a mastectomy on the same grounds.

Finally, respondents were asked: “Is there anything else you would like to tell us?” Strikingly, almost all had more to say, despite the stress of these interviews, and many made several different points. These detailed responses have been analysed for themes, and several key themes stand out.

First, as noted above, several people identified the need for much more education and information. Some comments linked lack of information and stigmatising of cancer patients:

“Cancer education is needed in the society. I wish I knew that it was cancer right from the start, [then] I wouldn't suffer that much. The education should be extended from primary school to universities. Another thing is that there is stigmatization of cancer patients, as people think that once you get it, you must die. Had there been no such feelings, patients would be free to share [experience?] and get advice.”

“More outreach programmes should be conducted. Some people think cancer is a communicable disease, so we need to make people aware of the disease and what the possible causes are.”

Some linked the need for a public health education strategy for cancer to the acknowledged need for screening:

“People in the village should be given education concerning the cancer also they should be examined for cancer because many people there don't know about cancer.”

“Women should go for screening more often, early detection of cancer greatly increases the chances for successful treatment.”

And another noted that there was a need to combat disinformation:

“Cancer awareness should be publicized, in order [for] people to get rid of talking nonsense.”

There were also comments on the need for specific information:

“I was wondering if there is any food that I can eat which can help with this disease.”

A second theme in these comments was the interlinked problems of costs of travel and treatment and associated impoverishment, and some considered remedies. Some cited examples of impoverishment:

Cancer disease has made her poorer economically because she sold some of her farmland in the rural area.

“I normally suffer a lot because I don't have capital to continue with my business.”

Even with free treatment at Ocean Road, other costs can be prohibitive or reduce the effectiveness of treatment:

“I don't have any relative here, the medicines are very strong, I need to eat fruits and good food. Therefore I need money.”

There was strong support for the principle of free treatment. Those with insurance recognised they were “lucky”. Some respondents noted the limits of current policy on free care, and its effects:

“I wish to go for check-up again but I cannot afford it.”

Transport costs were identified as a major barrier, and one person linked this to the fear of having to pay that kept some from accepting referral:

“From the time I got results to date, more than six months I haven't reported to Ocean Road hospital, because I do not have money. I can't afford even a bus fare to go to this referral. In addition to that people say that it is so expensive to deal with cancer so I decided not to go.”

Financial support was recommended, and it was noted this would help with continuing economic activity by patients:

Grant/loans to patients to be able to stay as an active contributor in the society.

The most common single theme in the responses was however the need to bring cancer treatment closer to home, to reduce costs, to help to increase speed of response, and to increase accessibility. Comments included services and also medicines and equipment:, for example:

“Government should try to extend cancer services to other regions or zones to reduce cost of transport and availability of chemotherapy and radiation. I understand that many patients are in the regions, they fail to come to Dar es Salaam.”

Cancer services should be available also to the District and Regional hospitals.

Cancer drugs should be available at Regional hospital pharmacies to reduce transport costs of patients going to receive it at Ocean Road Cancer Institute

“Those machines used for treatment should be available at rural areas hospitals so as to reduce the population of people from rural areas who come here for treatment.”

One patient noted that there is some cancer treatment available in the regions, but it can be costly:

“The government should consider providing a free cancer care at KCMC hospital in Moshi like here at Ocean Road Hospital because the costs are so high there.”

In addition to geographical distances, patients noted there were other sources of delays in the system which made patients' condition worse. These included slow receipt of test results:

“The tests results should at least come out in a short duration. Like my biopsy back home took 2 months.”

Equipment and supplies problems and queues were also mentioned: waits for equipment availability and long queues:

“The queue is big here at Ocean Road Cancer Institute for treatments like chemotherapy.”

“For example in MNH [Muhimbili National Hospital] we were using one bed for 3 people during chemotherapy sessions so at times you can't even sleep.”

And finally, in these comments there was deep appreciation for Ocean Road hospital's efforts, alongside the desire to spread this care across the country.

She thanks Ocean Road hospital for the good care and adding radiation machine.

Also commended the good services provided by Muhimbili National Hospital and Ocean Road Cancer Institute.

And there was even laughter at this mix of stress and care:

(Laughter) “what I can say, I am thankful for services provided at Ocean Road Cancer Institute and other hospitals should imitate Ocean Road Cancer Institute on how to care for cancer patients.”

4. Conclusions and recommendations

This paper’s key findings identify some reasons why many cancer patients start treatment at a late stage of the disease. Factors identified as barriers within the long pathways to diagnosis measured here included missed opportunities to pick up symptoms early, and many resultant moves between facilities as patients sought information and care. Most of this “churning” was not formal referrals: referrals became more common after diagnosis. Other factors included the burden of out of pocket costs of care and transport, and the fears and frustrations that led to recourse to alternative treatment and self-medication. The paper documents a higher cost burden for those in the lower income bracket without insurance coverage. Once a patient was diagnosed the treatment became free for many, but patients bore some costs to access to medication and tests, especially when facilities lacked essential prescribed items.

The Government should build the capacity of regional hospitals to be able to make and confirm diagnosis of cancer. Enhancement of efficiency and adequacy of service delivery at the lower tier facilities is necessary to reduce the burden on the patient’s journey. Cancer care also requires an efficient fast-tracking referral process for those diagnosed or suspected of having cancer. Some lower tier facilities should also be enabled with human resource and equipment to facilitate early and timely diagnosis as well as treatment. There is a need to assess how innovation in diagnosing and cancer treatment can lower costs of treatment and care, enabling timely referral and to reduce the overall costs of treatment and overhead expenses. Furthermore, the government should consider a grant or financial support for the low-income patients of cancer to facilitate their reaching to the hospitals and access appropriate treatment timely. Additionally, the foundations or associations for cancer survivors could also undertake fundraising activities with the private sector, and work with hospitals to support patients who cannot afford to reach the referral hospitals for timely access to care.

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